



Opelika CRS, VRS team up for School's Out Bash

by Ryan Godfrey

With beautiful skies overhead, the Opelika Children's Rehabilitation Service office opened the summer vacation season May 27 with this year's School's Out Bash for children with special health care needs.

Some 150-200 families from Lee, Tallapoosa, Macon, Chambers, Randolph, Russell, and Montgomery counties attended the event.

Children and families danced and sang karaoke while other kids tested their baseball-throwing skills at the dunk tank.

Sharon Henderson, parent consultant for Opelika CRS, coordinated the event, which has quickly grown to become the largest event held each year at Opelika's CRS office.

The party featured music from DJ Catalyst, balloon art from Dwayne "Dr. Magic" Reynolds, a petting zoo courtesy of Jubilee Farms, face painting by Sweet Cheeks, and appearances by McGruff the Crime Dog and birds of prey from the Auburn University Raptor Center.

If you missed out on the fun this year, don't worry. Plans are already underway for next year's celebration. Big kudos and an even bigger "thank you" to everyone who contributed to make this a special day for the many children and families served by CRS.



Above, two parents watch as their child throws a bean bag at a vendor's table



Left, Auburn University's golden eagle visit with children at the School's Out Bash

Below, CRS staff celebrate a child's winning toss



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Parent Connection is a complimentary newsletter published by Children's Rehabilitation Service for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

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From the Director's Chair



Hello Parents,

I trust that your summer is going well and wish you the best as your summer adventures and/or travels end and your plans for late summer/fall begin.

Speaking of the fall, I am excited to share that toward the end of summer 2015, CRS state office and district leadership staff, along with local staff, saw a need to engage in strategic planning to prepare CRS for future challenges and opportunities. This effort was embraced by all staff and included a staff survey that addressed strengths, weaknesses, opportunities, and threats to the division's services. Electronic surveys were sent to 227 CRS staff members, including parent consultants, on Nov. 2, 2015. The return rate for these surveys was 65 percent. The survey results were reported at a November leadership retreat led by former ADRS/Vocational Rehabilitation staffer Tammy Adams. Based on the survey results, the leadership/administrative team revised CRS' guiding principles (values) and mission and vision statements and developed 16 strategic plan objectives. The initial draft of a strategic plan was sent to all participants of the retreat for their review and to consider any revisions that needed to be made.

In January and February, the Administrative Team (leadership team) met again to evaluate the draft plan, ultimately narrowing the content to nine strategic plan objectives. I would like to share the following results of those meetings and the consensus garnered by those in attendance.

"Creating Partnerships – Building Futures" has been the vision of CRS over the years, and we decided to formerly name or label it as our vision statement. You'll find this statement on many of our existing CRS brochures.

A new mission statement also was developed: "CRS will partner with and empower children and youth with special health care needs, their families, and adults with hemophilia to promote their health, well-being, and maximum potential."

You will note that this statement aligns with the ADRS mission statement, which is "to enable Alabama's children and adults with disabilities to achieve their maximum potential."

Additionally, CRS guiding principles were established as follows:

Responsive – We will respond to ideas and challenges of clients/families, staff, leadership, and partners.

Quality – We will provide excellent service delivery.

Accessible – We will provide accessible facilities, program development, and services.

Encouraging – We will encourage client/families and staff to strive for success.

Communication – We will empower clients/families and staff through open and consistent communication.

Finally, the nine objectives that were developed are summarized here: Strengthen relationships and partnerships, develop relationships and partner with regional care organizations (RCOs), strengthen communications, recruit and train, increase awareness of CRS services, employ continuous quality improvement measures, enhance care coordination program, and establish certified electronic health record (EHR) technology.

By August, CRS will be providing the complete Strategic Plan to you within your districts, to include specific details of each objective, along with strategies, measures, responsible staff, and start/end dates. In addition, this Strategic Plan will be reviewed at the next State Parent Advisory Committee (State PAC). Our plan is to continue to share with and update you regarding this plan and allow you to contribute in ways that you can. Copies will be available at all of the district office locations.

Until then, continue to have a fun summer!

Melinda Davis, CRS Director

CrossFit 'Power Hour' for children with special needs

by Vera Spinks, CRS parent consultant

A little more than a year ago, the CrossFit Candor gym in Tuscaloosa implemented a weekly workout program specifically for local children with special needs.

My daughter, Kylie, who has cerebral palsy, and I felt inspired by others in the CrossFit Community who are thriving despite physical restrictions.

This led us to begin our CrossFit journey together once a week at Candor in an effort to improve Kylie's quality of life. The workout program for children with special needs soon came to be known as the "Power Hour" because everyone involved felt so empowered with what transpired during those 60 minutes.

Each Power Hour athlete has his or her own goals, strengths, and weaknesses. Using CrossFit movements, the athletes work hard within their abilities to achieve their goals. Many of these athletes would love to walk one day, while others aspire to lift objects in their chairs, or even move themselves from one place to another at will. Each of them is training specifically for these things, strengthening the muscles involved and moving forward to attain their goals.

Bradley, Cooper, Hank, and Andrew are the current boys of our group. While they differ in ages and current abilities, each brings his own



Athletes with disabilities are able to work out during 'Power Hour' at CrossFit Candor in Tuscaloosa



Trainers assist Kylie Spinks with lifting a barbell

strengths to Power Hour.

Bradley has amazing core strength and is recovering from a surgery that is only going to increase his future leg strength.

Cooper is the life of the party. His spirit and laughter are contagious, and with Power Hour he is now standing from a seated position and walking up to 30 steps at a time!

Hank now uses an awesome adapted bicycle to complete races as long as 13 miles, and he is training for a 30-mile bike ride this summer. He does burpees for reps that will blow your mind with their intensity, and he works harder than any athlete in our box.

Andrew is our resident "row master" and has dropped over a minute off of his 500M row time, allowing him to build strength and stamina. His mother reports that he now moves objects as large as huge dog food bags from one place to another — a feat impossible just a year ago.

Kylie is joined by Cindy to round out our female athletes. Cindy is our only adult Power Hour

athlete, and she rows with great intensity alongside Andrew. Her gains in strength are making a tremendous difference in her every day life.

We are so inspired by these Power Hour athletes. Whatever small amount of help we are giving them, we are paid in joy and inspiration.

We have the CrossFit Candor Community to thank.

This is at no cost to the families, and no coach receives payment for their services. Yet, every week you'll find University of Alabama students, parents with children, singles, and couples choosing to spend their evenings at Power Hour.

With the help of med balls, barbells, rings and Rogue bars for support, we are paving the way together toward independence and strength.

Isn't this what CrossFit is truly about? Stronger, faster, better able to live a functional life and loving on each other as we work.

You can follow [@crossfitcandor](https://twitter.com/crossfitcandor) on Twitter and Instagram to see these athletes at work.

DoD releases Disabled Military Child Protection Act policy

Reprinted with permission of the Special Needs Alliance - www.specialneedsalliance.org.

On Dec. 31, 2015, the Department of Defense released its policy implementing the Disabled Military Child Protection Act, providing guidance on who may assign survivor benefits to a special needs trust and the procedure for doing so.

President Obama signed the Disabled Military Child Protection Act on Dec. 19, 2014. This law allows a military parent to provide a survivor benefit for a child with a disability, and have it paid to a special needs trust for that child's benefit. Until this law was enacted, military parents of children with disabilities faced a serious dilemma at retirement – whether or not to choose the military Survivor Benefits Plan (SBP) retirement option for their children. The dilemma was that under prior law, the benefit could not be assigned to a special needs trust and could potentially interfere with the child's eligibility for means-tested government benefit programs such as Supplemental Security Income (SSI) or Medicaid.

Survivor Benefits Plan

Members of the military can elect several options to provide for a spouse or dependent child at the military member's retirement or death. The SBP will pay up to 55% of the military member's retirement pay to a spouse and/or dependent child when the retiree dies. The member can also elect a lower benefit at a lesser cost. The military member can select between coverage for a spouse only, a spouse and children, or children only. The member takes a reduction of about 6.5% in retirement pay for SBP for a spouse, and only about \$20/month for dependent children, including adult children with disabilities.

The prior law provided that the SBP could only be paid to a "person," and the Defense Department took the position that "person" did not include a trust for a child with disabilities.

Effect on SSI and Medicaid Eligibility

In addition to (or in place of) the SBP, a military member can elect an array of benefits for a child with a disability. In most cases, a child with a disability who is over age 18 can be designated as an Incapacitated Dependent

(DD Form 137-5) and be permanently eligible for military post privileges, as well as TRICARE health benefits. However, these military benefits do not include supportive living programs or vocational opportunities. Because SBP and TRICARE benefits are often insufficient to pay for all the help that may be needed by an adult child with a disability, the military family may need to look to other programs to provide for a child's needs.

If a child with a disability who is over age 18 has assets of less than \$2,000 and minimal income, the child will usually be eligible for SSI and Medicaid. Medicaid may duplicate TRICARE's health care benefits, but Medicaid "waiver" programs pay for a wide variety of services that TRICARE does not. Medicaid waiver benefits pay for supported living programs, in-home caregivers, mental health support services, day activity programs, job coaching and other services. TRICARE and Medicaid together provide a complementary mix of health care benefits and support services needed by many adults with disabilities.

SSI is a monthly cash benefit, up to a federal maximum benefit (FMB) of \$733 per month in most states in 2016, paid to an individual who satisfies Social Security's definition of "disabled" and who has less countable income than the FMB amount. Any unearned income over \$20 offsets or reduces the SSI benefit dollar-for-dollar. Earned income also offsets the SSI benefit, but not dollar-for-dollar. "Income" for SSI purposes is broadly defined, and is not the same as "taxable income." An individual who has too much "income" to qualify for SSI may still qualify in some cases for Medicaid waiver services. In many States a person's income must be less than three times the SSI benefit amount (\$2,199 in 2016) to qualify for Medicaid waiver services.

SBP payments paid directly to a child with a disability will offset the SSI benefit as unearned income. If the military member elected SBP for his or her child with a disability, and if the SBP payment exceeds the SSI benefit amount, the child with a disability will lose SSI and may also lose Medicaid health care and community

support benefits. In the author's home State of Virginia, and in many other States, if an individual's income exceeds \$2,199 per month, all supported living assistance, job coaching, respite care and other services provided under Medicaid waiver programs are lost.

Legislative Solution

The Special Needs Alliance began lobbying on this issue in 2007, which led to the introduction of legislation in 2009, which finally passed at the end of 2014. The Disabled Military Child Act (Public Law 113-291, amending Title 10, U.S.C. Sections 1448, 1450 and 1455) specifically authorizes military parents to elect that the SBP benefits for a child with a disability be assigned to a special needs trust. The trust must be a "first-party" special needs trust (SNT) that requires the trustee, upon the child's death, to reimburse the Medicaid plans of those States in which the child received Medicaid benefits during his or her lifetime, if any assets remain in the SNT at that time.

Policy Implementation

The Department of Defense issued its implementing policy on Dec. 31, 2015. A military member or retiree may now, at any time, irrevocably designate a first-party SNT created for the benefit of a dependent child with a disability as the SBP beneficiary to receive any SBP payments that would otherwise be payable to the child. The policy specifically addresses two situations:

During the life of the military member or retiree. The assignment to a SNT may be done at any time. After the death of the member or retiree. If SBP coverage for the dependent child was elected by the member during the member's lifetime, then the assignment to a SNT may be made by the child's surviving parent, grandparent, or court-appointed guardian. The policy does not address a situation where the member did not elect SBP because of the prior inability to assign the benefit to a SNT, or a situation where SBP was elected but subsequently

Please see Military, Page 11

Starting a small business?

A parent's perspective on customized employment as an option

by Vivian Spears, CRS parent consultant

So, you have this gift or occupation, and you've always had a dream of starting a small business, but there always seems to be something that gets in the way of taking that first step.

Well, don't ever let the stigma of disability hinder you from taking your next big step in life, including your exploration of the wide world of entrepreneurship.

If you are reading this newsletter and you are the parent of or a person with a special health care need or disability, let me share an option available in our sweet home, Alabama: microenterprise and customized employment.

I'm not an entrepreneurial expert or a current business owner. I'm just the parent of a young adult son with autistic spectrum disorder and an intellectual disability who has expressed interest in the possibility of starting his own business one day. We need to know how to get from A to B, plain and simple.

Through Parent2Parent networking, parent and professional collaboration, and parent advocates who are a part of the Parent Advisory Committee (PAC) in Jackson, we learned there are other families and individuals in the community who are also interested in learning this very same thing.

That's why we're sharing this information as an



Jackson PAC members attend a meeting on small business strategies



Rick Zapata, center, meets with Jackson PAC members, families, and professionals to discuss starting a small business

open diary to empower parents and encourage youth.

Two terms we will discuss are "microenterprise" and "customized employment." Microenterprise is really just another term for a small business, and customized employment is another term for self-employment. In other words, you own the business and you are the boss!

According to the Office of Disability and Employment Policy, **anyone** can own a small business if proper support, adequate financing, and paying customers can be secured. A disability should not hold you back from pursuing this route, and many individuals with significant disabilities already own and operate successful businesses.

Parents and caregivers with Jackson's PAC have embarked upon a training opportunity with Rick Zapata, regional agent with the Alabama Cooperative Extension System (Alabama A&M University and Auburn University), to participate in four free three-hour small business workshops. These sessions include the topics of starting a business from scratch, business economics and marketing, developing a

business plan, and business bookkeeping and taxes. Attending seminars like these will assist in providing a strong foundation in the world of business and help set you off in the right direction of becoming an entrepreneur.

The Vocational Rehabilitation Service (VRS) division of the Alabama Department of Rehabilitation Services has a wealth of information on matters of business and employment for persons with disabilities. Other agencies you may find helpful include the Alabama Department of Mental Health and the Alabama Cooperative Extension System.

Remember, you need to network with and support other parents and caregivers to develop the best possible support system available to assist and empower you.

Now that I've given you a glimpse of this exciting journey I've taken with my son, it is my hope that you will contact VRS to engage in your own conversation with a rehabilitation counselor to decide if this opportunity is a good fit for you and your family.

For more information about Children's Rehabilitation Service and to stay in touch with Parent Connection, please visit us on the web at rehab.alabama.gov/CRS and www.facebook.com/CRS.ParentConnection

Meet Jessica Havard, Mobile's new CRS parent consultant

by Jessica Havard, parent consultant

Hi! I'm Jessica Havard, the new parent consultant for Mobile's CRS office.

I have two children who are my inspiration for being here: Ethan, my 6-year-old son, who lives with epilepsy and ADHD; and Lily, my 5-year-old daughter, who has bilateral sensorineural hearing loss. After Lily's hearing loss diagnosis, I found my calling to help other families by sharing my experiences in advocating for her.

I started this journey wanting to work with children who are deaf or hard of hearing. I entered the interpreter program at Bishop State Community College.

One day while we were at the CRS clinic for an audiogram, I was drawn to a posting for a parent consultant position. I immediately felt this job was for me, so I submitted my resume before I left the clinic.

The past two years have been the rockiest, curviest roads of life I've experienced in my 29 years on Earth.

It all began when my husband and I suspected that our daughter, who was 3 at the time, wasn't hearing us.

I've always trusted my intuition as a mother, so I rushed to make an appointment with our pediatrician. After failing their basic hearing test twice, Lily was referred to an ENT/audiologist, which took a few months to see.

I prepared for the appointment by seeking out



Havard with her daughter, Lily

different resources for children with hearing loss.

When we finally saw the ENT, it wasn't as quick and easy as we had imagined. It turns out to be quite difficult to get a good audiogram on a 3-year-old.

So, we waited a few more months on a second appointment, which also proved inconclusive. Ultimately, we were ultimately referred to Nemours Children's Clinic in Florida for a sedated auditory brainstem response (ABR) test.

When we finally had the ABR test, it was a stressful three hours for all of us. The results confirmed Lily had mild to moderate loss in one ear and moderate to severe loss in her other ear.

We prepared for the next step of getting hearing aids, and Nemours recommended CRS to us. They explained the many wonders of CRS and how we could benefit from their expertise and services.

It was magical to witness Lily put in her hearing aids for the first time. In an instant, her world became one full of sound, and for the next week, she would make different noises just to hear what they sounded like.

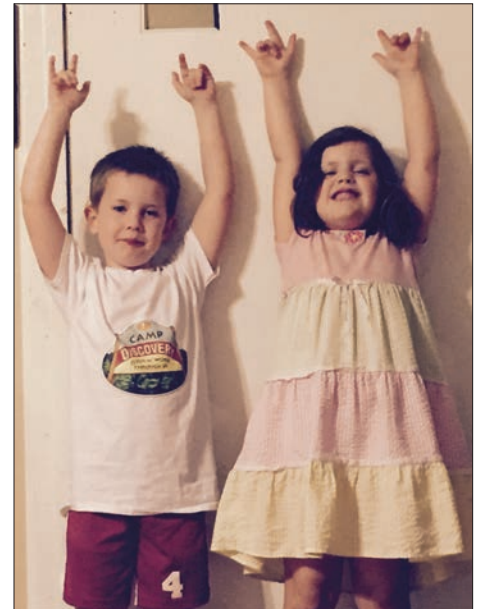
Since then, her hearing has progressively declined. Lily now has a moderate to severe loss in one ear and severe to profound in the other. With this bit of news, our family decided to learn American Sign Language (ASL) and integrate more with the Deaf community to help with Lily's communication and to provide her with the support of Deaf adults who she can better identify with.

We are all now deeply involved in the process of learning this beautiful language.

As a mother and a wife, I am extremely proud of our family's accomplishment, but I'm most impressed by our hearing son, who has flourished in learning ASL and goes to school and teaches his teacher and classmates new words and different facts about the Deaf community.

I've learned new things through that community, too, such as how it's incorrect to refer to a person with hearing loss as "hearing impaired" because using that term implies the person is damaged. I definitely don't see Lily that way.

I've also learned all about the pride within the Deaf community – they are proud of their deafness and it's an amazing way to raise my children. I want them to be proud of who they are and not let "disability" define them. I want my children to know that they CAN do anything they set their mind to.



Jessica Havard's two children, Ethan and Lily

Lily has very high aspirations for her future. She wants to be an acrobat, gymnast, and audiologist, and she knows she can achieve her goals regardless of her ability to hear.

Learning sign language is where I really started to figure out what it means to be an advocate for my child. This is a decision I've had to defend many times – to health care professionals, family members, and school personnel.

I've steadfastly advocated for my child and learned as much as I can about child development and ADA laws and shared personal experiences with my community.

I know that there are parents out there who need help finding their way or are looking for encouragement.

Many parents of children with special needs are lost in a sea of diagnoses, and I feel it is my calling to help people. This job has been the biggest blessing to me, and being here to help others gives me great joy. I'm here to open the world of connections and support to you as parents, and I'm eager to share.

Always know that I am here to serve and offer my experience and support. If you need help advocating or just need someone to lend an ear, feel free to call or stop by the Mobile CRS office, or email me at jessica.havard@rehab.alabama.gov.

I look forward to meeting you.

Travel with a child who is medically complex requires prep

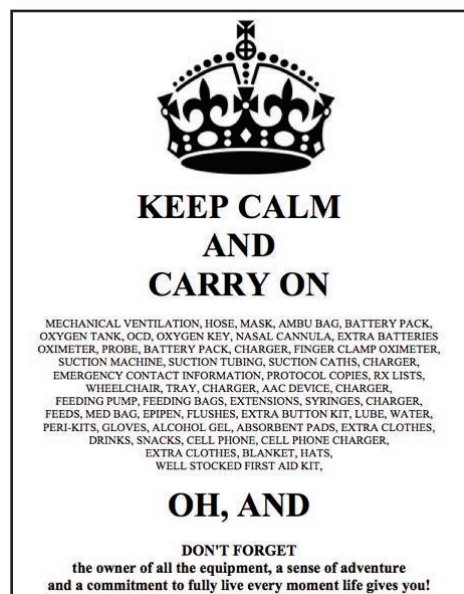
by Lana Jones, parent

Reprinted with permission from Complex Child E-Magazine

A journey of a thousand miles begins with a single step.

Keep calm and carry on.

These sayings are very true and wise. However, for my family, a journey of a thousand miles (and even one of 20 miles) has some different preparation and packing requirements, and our Carry On list looks like this:



You see, my family includes a loved one who is medically complex, and that changes some things!

Gone are my days of throwing a couple things in a backpack and heading off for the weekend or a week with friends. Our packing list for overnight travel now includes a 14-page checklist, an almost Herculean organizational effort, a sense of humor, a sense of adventure, and a great love of life. Our adventurous travel feats are made even more impressive because my much-adored daughter requires significant medical technology, full mobility support, and complex care to thrive.

An Alphabet of Experience

A – Alcohol gel is your friend for health. Hand washing and sanitizing supports health, especially in high traffic unfamiliar germ zones. Bring your own, bring lots!

B – Breathe. Take big calming breaths. Breathe in the adventure. Breathe!

C – Customs and Security Screening can be stretching experiences. Be kind, but don't be afraid to stick up for your loved one and take names if needed.

D – Documents are important! We carry a binder of documents just in case we need them – travel documents, legal papers, medical reports, doctors notes, confirmation of accessibility arrangements, medication lists, and copies of passports.

E – Extra time for all transitions. Most recommendations are set for ambulatory people with one or two suitcases, not people like us. Plan for extra time for transitions.

F – First-aid kits are handy things. Even people who are medically complex sometimes need the contents of a common first aid kit.

G – Go-bag. Don't leave home without it. We always have our go-bag in arm's reach. The contents of a go-bag will vary depending on needs, but ours contains the entrails of life and all supplies short of needing emergency transport to a hospital. Keep in mind that different hospitals in different places may have very different stock items than we are accustomed to having.

H – Hello adventure! Hello amazing and kind strangers. Hello crisis of today that will become the joke of tomorrow. Hello!

I – Invest in a comfortable backpack. If your hands are full of wheelchair handles or doing cares, a comfortable backpack can be a blessing.

J – Just ask. If you need help with something, just ask! Sometimes people don't know how or if to try to help.

K – Keep your essentials with you. If you need it, and it cannot be easily located or replaced en route or at destination, keep it with you.

L – Label things clearly with name and purpose. Just because enteral feeding equipment, suction machines, oxygen concentrators, mechanical ventilation, AMBU bags, and med bags are ordinary parts of our lives does not mean others are familiar with them.

M – Make many memories, and take lots of pictures! Some of our favorite travel memories are precious moments captured and have nothing to do with big venues at all.

N – No, you do not have to do EVERYTHING on your holiday. Do what works for you!

O – Organized packing and lists are helpful. I make mine with columns for packed, bag #, and repacked. Some of the entrails of life with a loved one who is medically complex are worth keeping close track of when packing.

P – Pictures are worth a thousand words. I bring a small photo album of my daughter's medical supplies, what they are, and what they are used for. It is often easier to understand why I cannot check or stow a large battery (or several of them in our case) if it is obvious that it is needed to help someone breathe, eat, clear his or her airway or monitor cardiac function.

Q – Quiet moments are essential. Plan quiet moments so you and your loved ones do not get overwhelmed. Recharge yourself as often as you recharge the batteries on the equipment.

R – Recognize that disability and medical complexity are viewed differently in different cultures and places. Depending where you are traveling, people may never have seen equipment like your loved one's ever, not even in a hospital. They may not have the words to ask the questions that you bring up for them. Staring and smiling are both universal.

S – Sometimes stuff happens. You may spell "stuff" differently and with four letters instead of five. Your travel may have some glitches. Deal with it, and keep going as best you can.

T – Treat others nicely. We take special "treats" for people who are seated near us on a plane or who have to wait behind us in lines, just to say "thank you" to them for being nice to us. These little treat bags are one of our favorite parts of travel planning. It is amazing what a little note, a Band-Aid, and a candy can do.

U – Use everything when going through Customs and Security. I hook my daughter up to all her essential equipment when going through Customs and Security so that there are fewer questions as to what her equipment does, and why I am insisting it stays with us through the travel process.

V – Variety is the spice of life. Have a Plan A, Plan

Please see Alphabet, Page 10

Life Course Theory ‘particularly poignant’ for CYSHCN

by Eileen Forlenza, director of the Family Leadership Initiative and AMCHP board president

As we pulled off the highway, we made our way down a picturesque country road that welcomed us with trees with outstretched arms.

It was almost as if we were getting a preemptive hug, a sense that perhaps we should prepare ourselves for a dose of emotion.

I was going on a site visit to a long-term residential group home for adults with autism or other profound intellectual deficits and I was going in with my eyes wide open.



Eileen Forlenza

I was far from my Colorado home, visiting an east coast state known for its history of excellence and dedication to children

with special health care needs.

My daughter Holly turned 23 this week, wedding yet another year between childhood and adulthood. One more year in her unique life living with complex health care needs.

As I prepared for this site visit, I convinced myself that it is logical that excellence in services for children will equate to excellence for adults – that service systems for children have mentored their counterparts in the adult system – exchanging best practices and lessons learned. However, logic doesn’t always prevail in the complex world of children and youth with special health care needs (CYSHCN). There is no window more clearly from which to view the truth of the

Life Course Theory (LCT) than to examine the quality of life of adults with autism and other developmental disabilities.

LCT is particularly poignant for children and youth with special health care needs (CYSHCN). Protective factors embedded in federal law on behalf of CYSHCN are demonstrated by Title V programs and the entitlement-based service delivery in newborn screening, early intervention services, special education, and health services for children and youth living in poverty.

The National Performance Measures (NPMs) asserted by the Maternal and Child Health Bureau are concrete protective factors that should set the rhythm by which a state designs its services on behalf of CYSHCN. While it is clear that Title V cannot do it alone, the NPMs provide the framework by which partnerships and collaborations can build effective systems.

Services offered by Title V agencies clearly offset the myriad of risk factors experienced by CYSHCN and their families. LCT states “today’s experiences and exposures influence tomorrow’s health,” which is another way of saying the trajectory of an adult with special health care needs is highly dependent on their childhood and adolescence.

With the integration of drinking fountains, schools and buses, our country also proclaimed that children should not be warehoused in state-run institutions simply due to complex health care needs.

For this, we should rejoice! As individuals with

disabilities were no longer cared for in large aggregate settings, they were integrated into their communities. The problem is we forgot to tell the community. Our schools, synagogues, churches, recreation centers and neighborhoods were simply not prepared. However, the focus of the bottom of the maternal and child health pyramid addresses this phenomenon. Building sustainable systems of care, anchored by population-based initiatives, assures that CYSHCN will have positive outcomes through the life course.

Leaving the long-term residential home, neatly tucked away in the rural countryside, I was choked with emotion. As I looked into the eyes of the non-verbal residents, I knew I was seeing the reflection of Holly.

At 23 years old, she was raised in the era of an enlightened country, supported by Title V programs, the Individuals with Disabilities Education Act (IDEA) and integrated communities. And yet, this is what Holly’s adult life may look like. Isolated, tucked away, predictable and living in an environment where being non-verbal is the norm. I ponder what her choices will be and how the system will hold itself accountable during cycles of budget restraints and political warfare.

And so, to my fellow colleagues who work tirelessly to improve the health of women and children: I implore you to embrace LCT when considering the journey of CYSHCN. Let us proclaim that as a community of learners we were prepared, innovative and wise.

Please add me to your newsletter mailing list.

Name: _____

Agency: _____

Address: _____

City/State/Zip: _____

Clip and mail to
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Children’s Rehabilitation Service
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For information about Family Voices, please contact the Alabama state coordinators, Susan Colburn, 334-293-7041, susan.colburn@rehab.alabama.gov, or Jerry Oveson at 251-438-1609, oveson@bellsouth.net.

Parade spotlights brain injury awareness

by Melissa Watson, CRS parent consultant

Each March is Traumatic Brain Injury (TBI) Awareness Month.

In north Alabama, a small group of teens and young adults with TBI and their families have attended regular support meetings, and during one of these gatherings, someone suggested the group participate in Huntsville's St. Patrick's Day parade to support TBI awareness.

Huntsville CRS Social Worker Suki Nielson and Alabama Head Injury Foundation (AHIF) Resource Coordinators Debbi Dane and Sandy Kiplinger met with adult, children, and adolescent TBI survivors and their family members to plan the event.

With so many different aspects of TBI awareness, the group narrowed the focus of the float to distracted driving. The stepfather of a youth with a head injury created the slogan **"STOP: Stay focused, Turn down radio, Obey traffic rules, Put down phone."**

Short Stop Screen Printing in Huntsville donated three banners for the truck and trailer for the float and provided a discount for screen printing shirts. The Huntsville Civitan Club created a donation fund for the T-shirts for persons with a head injury and family members. The same slogan on the banners was used on the tees, and the shirts were green – the official color for TBI awareness.

All of the participants were ready to walk in the parade, while those unable to walk the parade



Retiring CRS Social Worker Suki Nielson, center, poses with St. Patrick's Day parade participants

route sat on hay bales in the float trailer. The truck and the trailer were decked out in green balloons, streamers, and TBI banners. The group also made green ribbons to pass out along the parade route.

Last year, with all of the preparations made for the group's first time participating in the parade, a hard rain drenched everyone's hopes for a successful parade. Fifty people still participated in 2015's parade, but the floats moved quickly along the route for the few who waited out the storm.

With a 90 percent chance of rain for 2016's parade, many feared it would be a repeat of last year. Parade preparations included an accessible van for participants in wheelchairs, and the group had raincoats and umbrellas on hand for everyone.

Though the day was overcast, it stayed dry for the entire parade, making the event much more enjoyable for everyone involved. The floats moved more slowly, which made the message on the banners more impactful, as people actually had time to read them.

In fact, several participants noted some parade goers read the banner aloud. The parade was a success, and there are plans to make next year's event even better!

As it turns out, the parade didn't just promote TBI awareness.

One of the youths who participated in the parade had set a goal to walk the entire 1.7 mile route, walking every day for months to prepare herself. On the day of the parade, she walked the whole distance without assistance.

Inspired by her efforts, another mother told her son that she will walk with him every day to get him ready for next year's parade. In 2017, these participants will be ready for the parade come rain or shine.

Will you?



The TBI Awareness float is draped in large banners urging individuals to not drive distracted

A special night

by Emma Hereford

Gadsden CRS office coordinator

A Night for Our Stars – what a perfect theme for the Etowah County Children’s Policy Council first special needs prom.

Everyone deserves to feel special for one night and experience the prom and that is exactly what happened April 9. Music, dancing, pictures, food and fun filled the night.

More than 20 community agencies contributed to help make the prom a successful event. Seventy teens attended, with each one receiving a huge gift bag full of goodies and having his or her photos made by a professional photographer. They also had a wonderful meal catered by the Beautiful



Hereford with William and Jonathan Hazlewood

Rainbow Catering Company and Garden, a company comprised of teens and young adults with special health care needs who attend Gadsden City Schools.

Prior to the prom, the Southern Belle Boutique in Etowah County donated more than 50 new and “gently used” dresses for a special shopping day for all prom attendees that needed something to wear.

Flowers were donated for everyone in the prom court. Crowns, tiaras, trophies, and sashes adorned the prom king and queen as well as their court.

Several CRS staff members from Gadsden and Anniston – including Emma Hereford, Amy McQueen, Jennifer Jones, Holli Griffin and DeAnna McMurtrey – were on hand to decorate, chaperone, and clean up.

The effort was spearheaded by Emma Hazlewood, mom of twin boys William and Jonathan. Now 16, the twins have been enrolled with Children's Rehabilitation Service since they were two months old.



A CAPITOL IDEA

More than 35 young people with disabilities from around Alabama gathered in Troy earlier this summer for the 18th Alabama Governor's Youth Leadership Forum. The five-day forum, sponsored by the Alabama Department of Rehabilitation Services, teaches high school students with disabilities leadership and self-advocacy skills. Left, YLF delegates and staff visit with Alabama Secretary of State John Merrill on the steps of the Capitol as part of their trip to Montgomery to learn how state government works.

Alphabet

Continued from Page 7

B, Plan C, and Plan Z.

W – Water, lots of it. Drink enough safe fluids since dehydration is overrated.

X – X-rays with a person who is medically complex can be puzzling to security attendants – they may never have seen some of the extraordinary features our loved ones have. Try not to take it personally if they do a very thorough job of screening you.

Y – Yes, traveling with a loved one who is medically complex can be a lot of work, but in our experience it is so totally and completely worth it!

Z – Zzzzzzzzzz. Sleep enough when you can. It is a vacation, not an Iron Man Marathon.

This ABC list has been brought to you by the amazing adventures of Lana and Zhade. We have traveled together for the past decades, through seven countries, by plane, train, automobile, boat, canoe, foot, piggyback, zip line and wheelchair.

Our travels have been accomplished with the medical supplies and equipment needed to support the life of my child, who is both incredible and medically complex.

However, and perhaps most importantly, remembering always our sense of adventure and our commitment to fully live every precious moment life shares with us enriches our travels and our lives.

Traveling mercies to you!

Cool stuff: Smart sock monitor reads infant's oxygen, heart rate

by Melissa Watson, CRS parent consultant

There is a device called a pulse oximetry device that is often used in hospitals and medical offices throughout the country. It noninvasively measures oxygen saturation levels in the blood to determine how well oxygen is being sent to parts of your body furthest from your heart.

For most adults, sensors for the test are clipped on fingertips or earlobes. In the neonatal intensive care unit, monitors are placed on the foot.

A new company called Owlet manufactures smart socks for infants that use this same medical grade technology for the home.

The Owlet wireless smart sock (www.owletcare.com, \$250) is a device worn on a baby's foot to monitor heart rate and oxygen levels while he or she sleeps.

The information is transmitted directly to a smart phone. An alarm sounds if the device detects anything wrong.

The Owlet is expensive, but it is a relatively small price to pay for a little peace of mind, especially if this is a concern of yours.

Personally, I would not have hesitated to get this



The Owlet baby monitor wirelessly transmits vital stats to a linked smartphone or tablet

device for my daughter, Olivia, if it had been available when she was an infant.

When I finally brought her home from the hospital, she was still on oxygen, and I nervously watched her like a hawk to notice her little chest rise

and fall as she was breathing.

This device is pretty awesome, and I hope that advances in technology will soon make devices like these more affordable because I definitely can see a need for it!

Military

Continued from Page 4

forfeited by appeal.

Assignment Process

To assign the SBP to a first-party SNT, the member (or the child's surviving parent, grandparent or guardian, as the case may be), may write a simple letter to the Defense Finance and Accounting Service indicating that intention. Alternatively, the member may use DD Form 2565, Section X (Data for Payment of Retired Personnel). The letter must contain the name and Tax ID Number of the SNT, which in most cases will be the child's Social Security Number.

The letter of assignment or completed DD Form 2565 must be accompanied by a separate statement from an active, licensed attorney certifying that the trust is a SNT for the sole benefit of the dependent child with a disability, and is in compliance with all applicable Federal and State laws. This will serve as the verification

to the Department of Defense that the SNT receiving the assignment is the correct type of trust. The Department of Defense has provided a verification template for attorneys to use. The attorney's statement must be notarized and include the State in which the attorney is licensed, as well as the attorney's State bar number.

It is important to note that the SNT that may accept an SBP assignment is not the type of SNT that most families use as part of their estate plan. The SNT that must be used for the SBP is a first-party SNT (also often referred to as a (d)(4)(A) or self-settled SNT). There are very particular rules as to how a first-party SNT may be established and the required language that must be included. A member (or the child's surviving parent, grandparent or guardian, as the case may be) who wishes to assign the

SBP to a first-party SNT should consult with an attorney who is knowledgeable in special needs planning and familiar with this very specialized type of SNT.

About this article: *We hope you find this article useful and informative, but it is not the same as legal counsel. Good legal advice includes a review of all of the facts of your situation, including many that may at first blush seem to you not to matter. The plan it generates is sensitive to your goals and wishes while taking into account a whole panoply of laws, rules and practices, many not published. That is what The Special Needs Alliance is all about. Contact information for a member in your state may be obtained by calling toll-free (877) 572-8472, or by visiting the Special Needs Alliance online.*



CRS PARENT CONNECTION

Children's Rehabilitation Service
Alabama Department of Rehabilitation Services
602 S. Lawrence St.
Montgomery, AL 36104

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Check Out What's Ahead ...

Aug. 4, 2016

State Parent Advisory Committee

Description: Families from across the state meet with CRS and ADRS leaders, including the new ADRS commissioner, to discuss current initiatives. Topics of discussion will include a review the Strategic Plan. The meeting will be at the ADRS state office, located at 560 S. Lawrence Street in Montgomery. Meeting time is 10:30 a.m.-2:30 p.m.

Information: Susan Colburn, (334) 293-7041

Oct. 24-26 2016

2016 Early Intervention and Preschool Conference

Description: The Early Intervention and Preschool Conference is a two-and-a-half-day event designed to share information and develop skills for professionals and families who work with children with disabilities (ages birth to 5). The conference will be at the Montgomery Renaissance Hotel and Spa. Registration is \$80 for families and \$165 for professionals.

Information: Jeri Jackson, jbh50@aol.com

Feb. 24, 2017

16th Annual Alabama Autism Conference

Description: This conference focuses on understanding the unique and varied social and emotional skills exhibited by individuals with ASD and ways to support their development and functioning. Conference is held in Tuscaloosa and sponsored by The University of Alabama.

Information: www.training.ua.edu/autism

Local PAC meetings: Check your local CRS office for dates and times of meetings in your area.